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Genetic Privacy, Discrimination and Research in Washington State: Findings, Conclusions and Recommendations of the Washington State Board of Health Genetics Task Force

Introduction

The 2001-2003 Washington State biennial operating budget (enacted as Engrossed Substitute Senate Bill 6153 in June 2001) included a proviso (Sect. 220.8) for SBOH to convene a broad-based task force to “review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving human DNA.” The proviso directed the task force to report its findings, conclusions and recommendations with respect to the following four areas no later than October 2002:

- 1) the incidence of discriminatory actions based upon genetic information;
- 2) strategies to safeguard civil rights and privacy related to genetic information;
- 3) remedies to compensate individuals for inappropriate use of genetic information; and
- 4) incentives for further research and development in the use of DNA to promote public health, safety and welfare.

In response to the legislative mandate, the SBOH formed the Genetics Task Force (GTF). The GTF comprised 22 members and met five times over a nine-month period between January and September 2002. During this period the GTF received and deliberated over information from experts and interested parties on privacy, discrimination, and research with respect to genetic information. In addition, the GTF also reviewed the Department of Health’s (DOH) Newborn Screening Program draft privacy policies. (note: the report may need to include more of an analysis on this topic)

Information received by the GTF included analyses of existing state and federal legislation and regulations including but not limited to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rules, the American’s with Disabilities Act (ADA), the

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Uniform Health Care Information Act (Chapter 70.02 RCW), the Washington Law Against Discrimination (WLAD) (Chapter 49.60 RCW), and the Office of the Insurance Commissioner (OIC) Rules. The GTF also received presentations regarding the history of genetics-related legislation in Washington State, the historical practices of eugenics, legislative efforts in other states, and the potential effect of privacy and anti-discrimination policies on ongoing and future genetic research endeavors in Washington. This report summarizes the findings, conclusions and recommendations of the GTF.

Background

Legislative History

The Washington State Legislature considered 25 different drafts of various genetics-related legislation between January 1998 and March 2002. See Table 1 for a summary of the legislation. The scope of the proposed legislation varied significantly and included topics such as criminal DNA databases, health insurance practices, informed consent requirements, prohibitions against the misuse of genetic information, statutory definitions of terms such as ‘genetic information’ or ‘health care information’, the formation of review committees and/or task forces, and genetic testing practices. During this time period, few of the proposed bills that were related to genetic privacy and discrimination issues passed out of the legislature.

The debates surrounding the proposed privacy and anti-discrimination legislation predominantly focused on two areas: 1) the need to protect the privacy rights of individuals and to prevent the use of genetic information to adversely discriminate against individuals in insurance or employment; and 2) the effect of such legislation on genetic research and development and the biotechnology industry in Washington. One effort to reach a resolution to

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these debates was the establishment of the Joint Select Committee on DNA Identification in July 1999. This Committee included four members each from the House and Senate. The Committee expired in July 2000 without agreeing upon recommendations for further legislative action.

Subsequent legislative activity aimed at collecting information regarding the need for genetic privacy and anti-discrimination legislation included Section 220(8) of the 2001-2003 Washington State biennial operating budget. A proviso in this budget directed SBOH to create a broad-based task force to “review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving human DNA.” The task force created in response to this mandate comprised 22 members from various professional, consumer, and business associations.

Engrossed Substitute Senate Bill (ESSB) 5207, passed by the Legislature in March 2002, is the most recent legislative action taken by the Washington State Legislature with respect to genetic privacy. ESSB 5207 amended the Uniform Health Care Information Act (Chapter 70.02 RCW) to include a person’s deoxyribonucleic acid (DNA) and identified sequence of chemical base pairs in the definition of “health care information”.

Defining the Scope of the Genetics Task Force

In response to the legislative directive in ESSB 6153, SBOH approved a work plan for the GTF in October 2001. See Appendix A for a copy of the work plan. The work plan defined the scope of the GTF in a manner consistent with the legislative proviso. The Board asked the GTF to consider the potential of genetic information to advance scientific knowledge and improve health care practice in the context of privacy and discrimination concerns and to consider potential regulations regarding the use of and access to genetic information. The work

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plan included consideration of the collection, storage, and sharing of genetic information within the health and medical care systems as well as the use of genetic information in the context of health, life, and disability insurance and employment as balanced against the risk of harm to scientific research and development. The scope of the GTF excluded issues related to stem cell research and cloning.

Selecting GTF Members

Several of the individuals that SBOH invited to participate in the GTF represented the following interests: state and local public health, public and private purchasers of medical care, health insurance carriers, primary care physicians, pathology and laboratory medicine, genetic counselors, hospitals, genetic ethicists, institutional review boards, research geneticists, trial attorneys, medical research institutions, civil rights advocates, privacy advocates, citizens who have undergone genetic testing, parents whose children have been helped by genetic testing, the biotechnology industry, and experts in privacy laws and rules such as HIPAA. SBOH invited individuals who were presently or previously involved with existing SBOH or DOH genetics committees such as the Newborn Screening Advisory Committee, the Prenatal Screening Advisory Committee, and the DOH Genetic Services Advisory Committee. Other members represented relevant professional societies and associations. Table 2 is a list of GTF members and their affiliations.

Methods

The GTF met five times over the course of nine months: January 3, 2002, February 25, 2002, April 12, 2002, June 25, 2002, and September 4, 2002. All GTF meetings were open to the public. Three of these meetings served as opportunities to hear from experts or interested

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parties on specific topics. Table 3 summarizes the topics covered at the first three meetings. GTF staff supplemented information received at the meetings with literature and legislative research and consultation with legal advisors. Summaries of staff research were presented to the GTF in the form of the Genetic Privacy and Genetic Discrimination Matrix for Washington State, the Genetics Task Force Working Glossary, and meeting summaries. The matrix and working glossary are included with this report as Appendices B and C. *(note: the glossary needs to be finalized/approved)*

The GTF reviewed the charge in the budget proviso and the scope of work as detailed in the work plan at the January 3, 2002 meeting. Senator Rosa Franklin and Representative Al O'Brien attended this meeting and spoke about the Legislature's intentions when drafting the charge to the Task Force. Their comments provided a context in which the GTF could place the legislative mandate and helped to narrow the focus of the Task Force to specific areas of interest to the Legislature. Additional information received at the January 3, 2002 meeting included: an overview of previously proposed genetics-related legislation in Washington State; an introduction to the fundamentals of genomic science and the potential ethical, legal, and social implications of scientific advancements related to human genetics; an introduction to federal and state privacy laws and regulations such as HIPAA, the Governor's Executive Order on Privacy (EO 00-03), the Uniform Health Care Information Act (Chapter 70.02 RCW), and the Patient's Bill of Rights (SB 6199); an introduction to the Washington State Newborn Screening Program; and an overview of Institutional Review Board (IRB) practices and policies.

The GTF convened its second meeting on February 25, 2002. Representatives from the Washington State Office of the Insurance Commissioner (OIC) and the Washington State Human Rights Commission (WSHRC) presented analyses of regulations administered by each agency

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and explained how existing regulations may pertain to issues of genetic discrimination in insurance and employment. The OIC and WSHRC representatives also provided information on the incidence of genetic discrimination as reported to the OIC and WSHRC. Other presentations at the February 25th meeting included an overview of historical eugenics practices, an introduction to the potential misuses of genetic information, an introduction to the practices and policies of health insurers, and summaries of genetic privacy and anti-discrimination legislation in other states.

The third meeting of the GTF occurred on April 12, 2002 in conjunction with the Henry Art Gallery's Gene(sis) exhibit. The GTF heard from three panels of researchers on the topics of academic/basic science research, public health research, and private industry sponsored research. The panelists provided perspectives on the multitude of uses for genetic information in research and the development of genetic technologies to promote public health, safety and welfare. Panelists also addressed issues of oversight by local and federal agencies including requirements to protect human subjects through informed consent procedures, monitoring, and the maintenance of data security.

GTF members then developed a strategy for drafting conclusions and recommendations based on their findings from the previous meetings. It formed four subcommittees to draft reports from the perspective of different circumstances for obtaining and/or using genetic information. Table 4 lists the members of each subcommittee.

The fourth meeting, held on June 25, 2002, served as an opportunity for the subcommittees to present and discuss their conclusions and recommendations. The GTF aimed to reach consensus on the content of each subcommittee report; where consensus was not attainable, the GTF agreed to include minority opinions. After this meeting, the subcommittees

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revised their reports as necessary to reflect the views expressed by other GTF members.

Subsequently, GTF staff combined the revised subcommittee reports to form this report.

The GTF reviewed a draft of the final report at the September 4, 2002 meeting (add more here after the meeting).